

2000-2001 Long Term Care Council Public Forum Input

- The key themes that were heard repeatedly at Public Forums have been summarized in this document. It should be noted that these were statements made by consumers, their family members, advocates and other stakeholders. These were personal opinions and comments that have not been verified by the Health and Human Services Agency Long Term Care Council.

DATE	LOCATION	ATTENDANCE
November 28, 2000	Nevada City	45 individuals testified/ approximately 80 attended.
December 13, 2000	San Diego	42 individuals testified/approximately 84 attended.
January 11, 2001	Oakland	28 individuals testified/65 attended
February 21, 2001	Los Angeles	22 individuals testified/61 attended

ASSESSMENT ISSUES

- The current IHSS assessment process does not work for many individuals with Traumatic or Acquired Brain Injuries since their functional and cognitive limitations are not necessarily constant.
- The way IHSS hours are determined should be restructured to better meet the needs of individuals who have psychiatric disabilities.

COMMUNITY PLACEMENT SERVICES

- People need help in learning what services they are eligible for and what the
- General Medi-Cal eligibility information should be put on the web.
- Some programs have very helpful consumer information but consumers don't know how to get linked up with those programs.
- It takes too long and is too complicated for family members to get the information they need to help their parents find services. While some providers and agencies can be helpful, they only know about their particular service. Even health care professionals find it difficult to understand what the options are and negotiate arranging for them.

- Consumers and even local agencies don't know about some of the Medi-Cal waiver programs.
- Some mental health clients on SSI require short-term hospitalization from time to time. But in doing so, they become homeless because landlords evict them while they're hospitalized. This makes it even more challenging to find housing and start all over when they leave the hospital. **(The LTC Council researched this issue with the Social Security Administration. There is a little known provision that SSI can be continued to pay for housing during a hospitalization if the physician completes a specific form.)**

COMMUNITY CAPACITY EXPANSION

IHSS

- If the current limit on the number of authorized IHSS hours was expanded some nursing home residents could transition out of those facilities. Some do not need medical oversight; they just need 24-hour attendant care.
- It is very difficult to find and keep good IHSS workers. Workers are not reimbursed for their mileage getting to and from their employer and in rural areas this makes it even more difficult to find workers.

HOUSING

- The lack of supportive housing for the disabled makes it very difficult for some nursing home residents to transition into independent housing.
- The cost of housing in rural areas has increased significantly. But the housing formulas have not kept pace with these changes in some parts of the state.
- Many low-income individuals live in mobile homes. But those rents have also gone up significantly. If modifications are needed to make a mobile home more accessible or other repairs are required, banks won't make loans to finance those costs.
- Housing is essential. If an individual can't find housing, they can't access IHSS.
- The state should take leadership efforts in creating incentives for builders to include "Universal Design" in new structures. So many homes are designed with features that become major barriers to aging in place.
- More HUD housing for the disabled is needed. In some rural counties, there is no HUD Section 8 housing at all.

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DIVERSITY

- California is a very diverse state. More ethnic aging/long term care services are needed.

OTHER

- Many elderly have mental health issues that are not being addressed which limits their ability to remain in the most integrated community setting possible.
- Family caregivers need respite assistance. One family member who has a child with developmental disabilities noted that they receive 20 hours of respite a month through the regional center. But if she wanted to get away to visit family out of the area or have a real break, she would have to save up several months of this respite in order to do so.
- At each forum, individuals spoke to the difficulty they had in securing and using public transportation services for routine travel. Individuals who used paratransit noted how difficult it is to have to wait for two hours to be picked up and incidents that have occurred when the van failed to pick them up after it had deposited them somewhere hours earlier.

MONITORING & QUALITY ASSURANCE

- Family caregiving education is essential. Without it, family members will more easily become frustrated and potentially abusive. Out of ignorance, they may neglect needed care.
- More education needs to be done on advanced directives to ensure that abusive family members don't embezzle an individual's assets.
- Families who have a child with communication problems are very reluctant to use institutional respite services. The staff that would be interacting with the child change all the time and would not be able to understand or effectively communicate with her. Parents have requested assistive technology that would help in communications but this has not been forthcoming.
- Many parents are caring for their adult children who have developmental, psychiatric, traumatic brain injuries or other conditions. They worry about what will happen to their children when they are no longer strong enough to continue taking care of them.

OTHER

- In discussing the new incentives for the disabled to enter the workforce, consumers stated that Medi-Cal eligibility rules related to asset accumulation, income allowance

amounts, and estate recovery are major disincentives to encouraging individuals to seek employment.

- The difficulty in finding direct care staff came up repeatedly at all meetings from the full range of long-term care providers—home care through nursing home providers.
- Wage and health benefits for workers came up at all sessions.
- If an IHSS recipient goes into the hospital, his/her worker does not get paid. Yet the IHSS recipient will need that worker when he/she gets home from the hospital. One suggestion was that while that person is in the hospital, that IHSS worker could be used on a Rapid Response pool of workers to fill in for individuals who are sick or have other emergencies. In that way, the worker would continue to be paid but would be available again when their employer was discharged from the hospital.

INNOVATIVE PROGRAMS

- Rapid Response System within Alameda County Public Authority—If the IHSS worker doesn't show up for some reason, another worker is sent out to assist the individual. On-call workers are maintained to respond to these emergencies.
- In San Diego, an organization called "House Calls" does just that. Doctors make house calls and utilize new, portable technology to do tests at home. This results in a rapid response to a significant change in a patient's health care and avoids unnecessary emergency room visits.
- AARP members in San Diego shared information about a successful Money Management program that AARP has piloted in Texas. They noted the need for these types of programs as the population with cognitive limitations increases